

UNDERSTANDING THE IMPACT OF THE UN CONVENTION ON THE RIGHTS FOR PERSONS WITH DISABILITIES USING QUALITATIVE RESEARCH METHODOLOGIES

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Abstract

The UN Convention on the Rights of Persons with Disabilities (2008) has been hailed as a breakthrough in the field of human rights and advocacy for individuals with disabilities. Monitoring the implementation of the convention is a large task that will require an examination of research methodologies traditionally used in studying the effects of particular phenomena. This article argues that qualitative research methods which rely on the individual perspectives of persons with disabilities, their advocates, and family members will yield important data to further our understanding of the implementation of the convention. Additionally, we can identify best practices in the field of inclusive development to assist all persons with disabilities globally.

Key words: *qualitative research, inclusive development, persons with disabilities, UN Convention on the Rights of Persons with Disabilities.*

Problem Statement

Since 2008 individuals with disabilities and their allies around the world have been celebrating the passage of the UN Convention on the Rights for Persons with Disabilities, which offers a way forward in thinking about human rights for a group who are often left out, discounted, abandoned, or killed. With reason this event is cause for celebration, however, how will we know when we have fully realized the goals and intent of this important convention? What will count in terms of success? Who will be held accountable for ensuring better lives for individuals and their families? By what measure will we know for certain the Convention is serving its purpose? These questions are essential if we are serious about improving the quality of life for persons with disabilities. These questions also take on an added level of urgency when we are faced with uncertain economic global development and unequal levels of personal power, freedom and social justice.

Introduction to the Global Context

According to the World Health Organization, there are approximately 650,000,000 people with disabilities worldwide (Mont, 2007; Collier, 2010). However this number is an educated estimate for a number of reasons. One reason is that the concept of disability, and

its definition vary by culture, and in some instances, people might be reluctant to count their condition one way or the other way. For example, in China, there is no label for a head injury, such as traumatic brain injury, yet there must be individuals who have been thusly injured, especially when one takes into consideration the number of motor vehicles, the volume of traffic, and the driving population with little formal driver education. In particular, mental health labels carry stigma for most people, and to say that one has schizophrenia, for example, might bring your family dishonor, or community exclusion.

Daniel Mont (2007) has written about this exact problem, as have Amartya Sen (1999) and Martha Nussbaum (1997, 2006) when trying to find out how disability is counted and described for the purposes of economic development policy for the World Bank. Specifically, Mont carefully explains the past limitations of surveys that asked respondents to comment on their impairments using a medical model approach. Questions might be ignored, overstated, embellished, or misunderstood. Recognizing the power of the World Bank and its ability to fund projects based on “real data”, i. e. quantitative data and statistics, it is critical that the information is accurate. At the same time, we know that individuals have individual experiences, and those experiences can be powerful lessons for us.

In contrast, the disability studies model promotes a social understanding of disability and how societies think about persons with disabilities. The field of disability studies is a relatively new area of critical inquiry that promotes a social model of understanding people with disabilities in the context of their families, communities, and societies (Gabel & Danforth, 2008; Valle & Connor, 2011). Using a social model enables researchers to study how persons with disabilities are included in their home, community, and workplace.

There is a tendency for us to seek specific answers to questions that may, in fact, have complex answers. For example, we want to know how many people can read in a particular country. The UN reports impressive data sets for each country, and you can determine health factors, literacy rates, mortality rates, and more, all from charts and statistics reported through EdStats (UN Edstats, 2011). No doubt this is useful information, and it is made even more useful with tools and linear regression models. But what we seldom are provided are real human stories that give us a better sense of *how things really are out there*, and what needs to change (if anything).

Object and Aim

The purpose of this article is to examine stories of individuals with disabilities and specific contextual situations to understand how important qualitative research methods are for developing theories of best practices for supporting persons with disabilities according to the articles of the UN Convention on the Rights of Persons with Disabilities.

Methodology

A major principle in educational research is that an important research question is first identified and then research methods are selected to match the research question (Gall, Gall, & Borg, 2002, as cited in Giangreco & Taylor, 2003). Using interviews, participant observation, an extensive review of research literature and document content analysis, several coding themes were developed to organize the data.

Here are a few examples of what I mean:

From Kiev, Ukraine. The grand civic hall of Kiev is used for a wide range of celebrations in the city. It is a modern building with tall pillars at the entrance, and crystal chandeliers on every floor. As a guest I attended the 10th Anniversary of the Open University of Human

Development of Ukraine in 2008, which was a daylong gathering of students, dignitaries, citizens, and guests, followed by an elegant buffet in this large building. It was raining heavily outside and most people took shelter immediately. At the end of the program, before the dinner, one lone student was sitting in the entrance hall, trying to be comfortable on a concrete bench. Sasha (pseudonym) was someone I met earlier at the university, and I knew that he had just graduated with a law degree, and he also has cerebral palsy. His speech is quite hard to understand (even if I spoke Ukrainian, which I don't), and his interpreter worked to help him communicate with others. He was clearly agitated and seemed distressed. My host and I approached him to find out what was wrong. Nearby, a custodian was speaking loudly into a walkie-talkie and seemed upset too. Sasha explained that the custodian told him to leave the great hall lobby because he was "cluttering up the place and looked like he didn't belong." While the performances were continuing in the auditorium, Sasha, who had also been on stage as an awardee, took refuge in the lobby before the crowd emerged. The lobby attendant did not want him to be sitting in the lobby and had come close to picking up Sasha and forcibly moving him.

My host, an official at the university was visibly shaken, and after having harsh words with the lobby attendant, explained to me that it was another example of the way persons with disabilities are treated. She said, 'There is no way he (attendant) would dare to speak to me like this, let alone ask me to leave the lobby! It is only because Sasha is disabled and this person thinks he does not belong at a celebration, especially one for the university!'

Meanwhile, Sasha was talking with his interpreter and others who were now mingling around him. He was clearly upset still, and discussing the next step of filing a complaint through the university. The lobby attendant was in the vicinity and did not look too happy about the scene.

From Xi'An, China

Xi'An was the original capital city of ancient China, and the remaining walls around the city are an enduring reminder of its place in history. In the central core of the city there is an area that is home to thousands of Muslim Chinese, with an ancient mosque, numerous crowded stalls with ethnic foods and goods for sale. The market area is lit by single light bulbs, dangling over the narrow alleys. One evening, during a downpour, I saw a young woman propel herself across the cobblestones while sitting on a wooden sled with wheels. She had foot-long sticks taped to her hands, and she dug them into the walkway to move forward. Her shoulders were broad and athletic; her legs were tiny and tucked underneath her. She rode her sled almost as a skateboarder would in an urban setting in North America. I was stunned to see her in motion; she was the first person I saw in China who had an obvious disability, and who was mobile in such an effective way. This was not a high tech invention, but a homemade transportation rig. Who was she and where was she going? Before I could blink she was gone.

From Doha, Qatar

The citizens of Doha, Qatar are reputed to be among the richest in the world. The ruling Royal Family has made a commitment to educate all citizens, providing the very best of tertiary education to anyone. Beyond "Education City", a campus with western top-ranked universities maintaining satellite campuses, there is a center of progressive education for Qataris who have disabilities. The Shafallah Center provides educational services, rehabilitation and counseling for children and adults with developmental disabilities. Her

Highness Sheikah Mouza bint Nasser al Missned has dedicated her resources to providing a state of the art facility, with advice and consultation from the “best of the west”. In the center, parents can find information, supports and services all tailored to their individual needs.

Previously in Qatar, children with disabilities were sent to institutions and schools abroad, primarily in Europe, in order to receive an education. Sometimes families rarely saw their child again, and the family unit was disordered due to the distance created. Sheikah Mozah viewed this as a heartbreak no family should have to endure, and she made it a priority to fund a local center for her citizens.

Since its inception, the Shafallah Center has been funded with millions of dollars, and has ballooned into a campus that rivals the best. Initially most of the staff was professionals hired from the west, with a plan to train Qatari citizens. This is a goal for many reasons: to build local capacity and understanding among Qatari citizens; to provide an education for Qataris that is uniquely Muslim and respectful of culture in Qatar; and, to fully integrate students with disabilities into Qatari society. When visiting the Shafallah Center one is left with questions as to how this is working for the students and families. How is a rehabilitation and education program styled after western programs influencing families in Qatar?

From the United States

In the United States there have been several recent cases of abuse and neglect for individuals with disabilities. One prominent case involves a behavioral intervention school in Massachusetts that has used aversive behavioral techniques for decades (Wen, 2011). Students have died while under their care, as a result of electric shock cattle prods, wearing specially designed helmets that emit harsh auditory stimulation, squirting noxious substances into nostrils, being held in four-point restraints for days on end, and random shocks that exceed the industrial standards of care for animal livestock. It is reported that the cattle prods used at this school are designed to provide a shock that is twice the legal limit for cattle. A Washington D.C. non-governmental organization Mental Disability Rights International successfully petitioned the United Nations Special Rapporteur, citing these violations as human rights abuses using the Geneva Convention Against Torture. While the school is still operating, the Director, Dr. Matthew Israel was forced to resign (Wen, 2011). A court-appointed monitor is in place to keep an eye on the situation. The irony is that the former Behavior Research Institute (BRI) was still under court supervision and renamed the Judge Rotenberg Center (JRC) when these recent charges were laid. Clearly government oversight in this situation was lacking.

These examples from Ukraine, China, Qatar, and the United States are completely different in scope and defy quantitative surveys and polls. In order to fully appreciate these experiences, one must be immersed in the situation, with reliable informants, and enough time to become familiar with the scene. No doubt there are multiple understandings of the situation, and this adds to the complexity of our understanding, rather than diminishing the results of the study (Bogdan & Biklen, 2011). Personal stories and experiences are complicated and need to be fully understood in context.

Results: Why Qualitative Research is More Important than Ever

Qualitative research methods provide us with the tools to delve into complex situations. We can learn from individuals using interview methods; we can observe as participants or non-participants to understand the situation, and we can stay grounded in the data by researching cultural norms, attitudes, and checking our data with local experts. There is a rich tradition of using qualitative methods in the field of disability studies (Bogdan & Biklen, 2011; Giangreco

& Taylor, 2003; Grut & Ingstad, 2005) and, one could argue, the field has evolved because of the power of individuals telling their stories using a qualitative approach (Gabel & Danforth, 2008). In fact, we have learned directly from persons with disabilities what is important to them, how best to support individuals and families, and how best to educate children with disabilities (Kluth, 2011).

The field of disability studies has evolved toward a social model of understanding disability as a result of using qualitative methods of inquiry. The medical model of disability is now outdated as a way of interpreting the lives of people with disabilities. In keeping with advances in the field, the World Health Organization has adopted a social model of disability as a way of defining disability. This is a critical stance that has empowered people globally. What has not necessarily evolved to the same degree is the way we learn about people with disabilities and the appropriate research methods to do so. This has become a problem when we consider how to monitor progress of people with disabilities in the context of the UN Convention on the Rights of Persons with Disabilities.

To date the agencies that fund large scale studies are mostly concerned with quantitative data sets that enable statisticians to compare countries for global monitoring purposes. This is important data. The questions that are raised from such data gathering techniques are also important. But what are left out are the personal and individual stories that are indicative of social and cultural norms. These events are important to understand as well, and often cannot be compared with anyone else's experience. But taken as a whole, themes can be developed when enough information has been gathered. So, for example, we can learn of the inventiveness of citizens in a particularly poor country, as a way of coping with limited resources. We can learn how a particular community supports mothers of children with disabilities by sharing time and ideas. These notions of support are often overlooked in large-scale studies, and do not equate easily to a formula for GDP and aid monies. As one advocate from Bangladesh puts it: "we may not have money and resources, but we have a lot of *people resources*" (personal communication, 2009).

We know from disability studies that communities of people can inform and support each other in ways that do not seem apparent in terms of dollars spent and education levels achieved. This is important for our understanding of developing nations and the way these countries support individuals with disabilities. Often the concern of developing countries, among others, is that they will not be able to afford support for their citizens with disabilities. Some people take this argument further, and state their objections to providing precious resources for persons with disabilities based on inequity across the population for health care, food, and shelter. While these concerns are legitimate on face value, how are people coping with disability as a primary factor? If there are 650,000,000 people with disabilities worldwide, and approximately one billion people living in failing states (Collier, 2007), what can be done to understand the situation of these people and their resource scarcity?

One effective means of understanding particular situations is a technique employed by Mental Disability Rights International advocates, where they receive a nomination to study a particular country and its policies and practices for individuals living in dire circumstances. In fact, the reports generated by MDRI have been influential in advancing human treatment for persons in several countries (for example in Romania, Hungary, Mexico, Paraguay, Viet Nam, to name a few), and have influenced member states of the European Union when determining membership of states under consideration (see www.mdri.org for complete reports). These advocates enter the situation and study the conditions people are living in. The researchers rely on cultural workers as informants, and fact-check their information with documents, interpreters, and numerous visits. The robust nature of this inquiry has yielded huge results for persons with disabilities.

Another nongovernmental organization of equal importance is Mental Disability Advocacy Center (MDAC) based in Budapest, Hungary. This group of legal advocates has reported on conditions in Croatia, Slovenia, Russia, and other central and eastern European countries. Additionally, this organization provides legal assistance and training for families of individuals with disabilities (see www.mdac.org for further information.)

The UN Convention on Rights for Persons with Disabilities will rely on special rapporteurs to provide and interpret results on behalf of persons with disabilities. It remains unclear as to how individual states parties will collect data, analyze the data, and report findings to the committee. Another issue on the front page of international advocacy efforts is the use of electroshock against prisoners and people with disabilities as a punishment. For example, in Turkey and Argentina, until recently it was a common psychiatric practice to use electroshock treatment, *without anesthesia*, to “teach adults [with a disability] a lesson.” The international standards for care within the psychiatric mental health community were not being applied in certain countries, even though the primary psychiatrists knew this would violate current practices and would certainly cause significant pain (MDRI Turkey report, 2008; MDRI Argentina report, 2007).

Why do we have so much attention on persons with disabilities? Given this group is the largest minority in the world, we have an untapped sector in all societies that have been marginalized, ignored and underappreciated. With a commitment toward education, health care, nutrition, public safety and security, these individuals and their families can be contributing members of society. In the international development aid system, nongovernmental organizations (NGOs) tend to view their mission as a single set of outcomes, such as providing wells for a village, better nutrition, immunizations, education, and organizational structures for civil society. A new framework of *inclusive development* considers all aspects of human growth and wellbeing within a society, with a particular emphasis on persons with disabilities as contributors with capabilities (Nussbaum, 1997, 2006).

While these examples are harsh and obviously detrimental to life and well-being, more subtle forms of discrimination can be seen in our society. Here are a few to consider: the use of the word ‘retard’ in everyday language in the media; a lack of physical accessibility; selective genetic counseling to terminate pregnancies for “suspected disabilities”; and, neighborhood opposition to group homes and community care facilities continues. How can we turn the tide against people with disabilities and support each other to become valued members in our society?

There are positive examples to study and inform our understanding, using Nussbaum’s Capabilities Approach (2006), which offers ten factors to promote the needs of people with disabilities, in order to live a fulfilling life. Nussbaum’s work is an *aspirational* set of ideals, listed below in Table 1. If we combine these ideals with the guaranteed rights under the UN Convention, we have a newer, positive way of thinking about supports for our most vulnerable citizens. If we choose to support people with disabilities in our personal lives, in our communities, and in society, here are some ways we can use the Capabilities approach as set of “golden rules” to live by. We can choose to support people with: inclusive education at all levels; community living residences with freely chosen companions; supported employment with access to real work and wages; healthcare in the community that is the same as what all citizens receive; a meaningful life with loved ones in the community.

While we are developing our societies to include our most vulnerable people, we can learn much from one another. A clear way to learn is to share personal stories of achievements, and the best way to do this is by employing qualitative research methods, and communicating this information electronically, in print form, and in conferences. In our global world this is quite possible.

Table 1

Capabilities in the Life of a Person with a Disability

<p>1. Life Lived to the fullest Articles 10, 15, 25</p>	<ul style="list-style-type: none"> • Life spans of WHO expectations for industrialized countries • Quality of life and end of life decision-making
<p>2. Bodily health Freedom to pursue a healthy life without restraint Articles 10, 11, 14-17, 19, 25, 26, 28</p>	<ul style="list-style-type: none"> • Food and nutrition for wellness • Access to health care in community • Participation in wellness activities in community
<p>3. Bodily integrity Articles 10, 11, 14-17, 19, 25, 26, 28</p>	<p><u>Freedom from:</u></p> <ul style="list-style-type: none"> • Sterilization forced • Do not resuscitate orders • Experimental drug and surgical treatments • Abuse • HIV infection • Aversive behavioral therapy
<p>4. Senses, imagination and thought Freedom to experience nature within natural ecosystem Articles 8, 10, 14-21, 24, 28-30</p>	<ul style="list-style-type: none"> • Community living • Education for all by 2015 (UNESCO) • Opportunities for exploration of environment • Sensory stimulation • Guaranteed a form of communication with technology
<p>5. Emotions Freedom to express natural emotional life and intelligence Articles 8, 12, 14, 18, 19, 21, 23, 24, 28-30</p>	<ul style="list-style-type: none"> • Emotional lives interpreted as “appropriate behavior”; not dangerous • Permitted to marry and have families, or adopt • Seen as emotionally mature
<p>6. Practical Reason Viewed as capable, competent, sentient beings Articles 5, 12-14, 17, 18, 21, 22, 28</p>	<ul style="list-style-type: none"> • Legally competent (i.e, rule of law, court system, witnesses) • Capable of supported decision-making with guardians who assist • Personal Futures planning • Realistic to dream beyond present
<p>7. Affiliation Freedom to associate with all species of choice Articles 5-7, 12-14, 17, 21-23</p>	<ul style="list-style-type: none"> • Living with family and chosen friends • Inclusive communities • Inclusive recreation and leisure
<p>8. Other Species Respect for all species, not just own Articles 5, 10-18, 22, 23</p>	<ul style="list-style-type: none"> • Living arrangements that are in one’s control or freely chosen • Given opportunities to investigate or explore nature • Animals viewed as companions or loved ones not just in servitude
<p>9. Play Inclusive opportunities for play and recreation Articles 5, 8, 9, 18-21, 24, 30</p>	<ul style="list-style-type: none"> • Recreation is unlimited and available • Accessible play spaces or adapted equipment
<p>10. Control over one’s environment Dignity of space, place in community and society Articles 5, 8, 9, 12-18, 30</p>	<ul style="list-style-type: none"> • Living wages and opportunities for employment • Viewed as competent to own property • Permitted to speak or use technology to communicate • Socially Valued roles in society

Conclusion

In summary, people with disabilities, locally and globally continue to face enormous obstacles for full participation in society. Constituting the largest minority in the world, which cuts across all ethnic, cultural, economic and social ties, there should be a stronger emphasis placed on public education, health, and inclusive community living in order to incorporate all citizens. With protections and rights afforded by the United Nations it is within our reach to attain these goals in our society, and by assuming that people are more capable, we can benefit with everyone's participation. It is essential for us to learn from each other by sharing this information to inform our practice in support of people with disabilities. Qualitative research methodologies provide us with the tools, techniques, and perspectives to better understand the perspectives of people with disabilities, and can be useful in studying the implementation of the UN Convention on the Rights of Persons with Disabilities.

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